
Book reviews

Should the Baby Live? The Problem of Handicapped Infants

Helga Kuhse and Peter Singer,
228 pages, Oxford, £12.50, Oxford
University Press, 1985.

Drs Kuhse and Singer have written a forthright and logically argued statement in support of what has been called the 'selective treatment' of severely disabled infants. Unlike many other books on this topic, the philosophical arguments are expressed clearly and concisely so that paediatricians who grapple with these dilemmas should find them easy to follow. I welcome this addition to the rapidly expanding literature on a controversial subject and agree with most of the views expressed, but I am sure that many will dislike it intensely. Some will find it disturbing and even offensive because, for some of these difficult and tragic situations the authors make a case for the legislation of infanticide. I am reminded of an article written by Dr Robert Morison 15 years ago in which he pointed out that: 'We are being driven towards the ethics of an earlier period by the inexorable logic of the situation, and it may only increase our discomfort without changing our views to reflect that historians and moralists both agree that the abolition of infanticide was perhaps the greatest ethical achievement of early Christianity' (1).

The book begins with descriptions of recent cases that came to public attention and legal argument in the UK and the USA, those of Dr Leonard Arthur and the Babies Doe respectively. Although in many ways atypical, they are used to identify some of the difficult questions and to provide a background to subsequent discussion. The authors examine how the traditional doctrine of 'the sanctity of

human life' and the more recent insistence on 'equal human rights' have led to the widely held view that all human life is of equal worth. Such a view may be the simplest way to answer difficult questions about the treatment of severely disabled infants but the authors expose its absurdities in clinical practice by reviewing the American Baby Doe Legislation and its shaky foundations in ethics.

To illustrate changing attitudes, they discuss the treatment of the severe forms of spina bifida during the past few decades when improving surgical skills and modern technology brought great optimism followed by disillusionment. Decisions to treat or not to treat based on quality of life considerations are made in the expectation (and hope) that infants not treated will die. The fact that some do not die but may become even more tragically handicapped, along with the differences in mortality from hospital to hospital, indicate the enormous variation in attitudes and an inherent hypocrisy towards 'allowing to die'. The authors discuss the 'fiction' that killing and letting die are ethically different and point out that to give up this distinction means surrendering belief in the sanctity of life. Furthermore they challenge this Judaeo-Christian doctrine as 'speciesist' if limited only to human life and claim that it is as indefensible as racism or sexism. Perhaps this is going a bit too far. Nevertheless I agree that in our zeal to treat virtually all infants aggressively without regard to their future quality of life and the consequences to the family, or in our reluctance to accept death we are showing infants far less compassion than we would show to animals in similar circumstances. Absolute adherence to the sanctity of life makes no sense to most families facing these individual tragedies whatever their religious views, and, as the authors point out, it is also increasingly irrelevant to members of a public who

do not necessarily accept religious beliefs as the source of all ethical wisdom.

Having argued that newborn infants do not have an absolute right to life, the authors devote a chapter to weighing the interests of the child against those of the family and society. This utilitarian analysis includes the observation that the experience and stress of caring for a severely disabled child may cause the parents to deny themselves a further child or children who would probably be normal. All paediatricians know of such parents and their chronic sorrow but this important and tragic consequence is frequently ignored or underestimated. They also point out the incongruity of devoting apparently unlimited resources to saving the lives of severely damaged infants at the same time as restricting or reducing the funds available for their future care.

Their overall message is a powerful one, 'It would be better for the child, family and society if some infants were not to survive. If parents and doctors agree, treatment should be withheld or stopped and the child allowed to die'. I believe that the majority of practising paediatricians would agree although with variation in interpretation, undoubtedly influenced in recent years by the activities of 'pro-life' activists and the intrusions of the law. But Drs Kuhse and Singer go further. They refer to the 'Limitation of Treatment Bill' proposed by the Brahmans (2) (not by Prospect as stated) and argue that, if necessary, the infant's life should be ended in a 'swift and painless manner'. I agree that this is less barbaric than allowing an infant to die a prolonged and painful death and I admit that 'inexorable logic' is pushing us in that direction but I think most paediatricians would still be cautious about having these difficult decisions made any less difficult, particularly through involvement of the State. There is some merit in agonising over

the dilemmas and debating the issues with care.

Like Kuhse and Singer I believe that these decisions are best left to doctors and parents using appropriate consultations and counselling, with the courts being used only as a last resort to resolve serious disagreements or where there have been abuses of trust. To involve the State in sanctioning legal killing might erode much of this trust, even if such a law might protect doctors from accusations of murder. Absolute certainty in prognosis is impossible. With modern skills and technology we now err on the side of 'wrongful life'. Doctors, parents and society would need to be confident that such a law would not tip the balance towards 'wrongful death'. What parents and doctors need from society is not necessarily a new law but more compassion for the afflicted infant, more understanding for the family and considerable latitude for doctors in working out these dilemmas in the best interests of the infant and family. It would indeed be ironic if a Limitation of Treatment Bill were to become necessary because legislation like 'Baby Doe' or the efforts of 'pro-life' activists were seen to be increasing the suffering of infants and the harm done to families.

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References

- (1) Morison R S. Death: Process or Event? *Science* 1971; 173: 694-698.
- (2) Brahams D, Brahams M. The Arthur case - a proposal for legislation. *Journal of medical ethics* 1983; 9: 12-15.

High Technology Medicine, Benefits and Burdens

Bryan Jennett, 245 pages, London, £8 including p&p, The Nuffield Provincial Hospitals Trust, 1984.

One of the delights about Jennett's writings is how readable they are. In the literature on high technology that is not a trivial point since this important area of medicine seems to be increasingly surrounded by largely indigestible papers, proceedings and books. The language of high technology medicine is often a little baffling; that of technology assessment frequently beyond

comprehension.

Certainly if the desirability of more and better technology assessment, the central theme of Jennett's book, is to be recognised by politicians, public and medical pundits then communicating the essential ingredients of the process is required. That is what Jennett succeeds in doing in this book.

He takes us through the relationship, between technology and medicine, including some well presented practical examples. He examines various attitudes to technology. In the core of the book he considers the 'benefits and burdens' of technology in health care and what has been and what can be done to manage technology.

On his very first page, he gets off to a good start when he defines technology as 'the use of tools'. How refreshing this is in comparison to so many other definitions currently promulgated by various different, apparently authoritative, bodies.

He is also ready to point the finger when and where he believes it is necessary. 'For many doctors conspicuous private consumption (for example a Rolls Royce) has been replaced as a status symbol by conspicuous public consumption' (p27). Many observers of health care have been saying something the same (but not as eloquently - and not as tellingly as when it comes from the dean of a medical faculty).

Central to his view is the need to get the balance right between benefits and burdens. He writes in a passage which sums up the book:

'There is seldom a clear dichotomy between the useful and the useless. More often it is a matter of relative worth, weighting the benefits, risks, and costs for individual patients, and taking account of how many in the community stand to benefit and what opportunities of bringing benefit to other patients would be forgone (p 230)'.

For those concerned with the ethics of technology assessment a comment in the middle of the book (p 132) brings out clearly the opportunity cost and indeed senselessness of not assessing technology.

'Granted that some technologies are of acknowledged benefit it is surprising how wide are the variations in their availability and use, even in different parts of Britain where there is a unified system for providing health care. . . This patchy and piecemeal adoption of effective technical innovations should

be a source of embarrassment to the profession and to the health service.' Such disparities across the country cannot be considered ethical.

He goes on to suggest that there are five main reasons why the deployment of high technology can be inappropriate. It may be (i) unnecessary; (ii) unsuccessful; (iii) unsafe; (iv) unkind; or (v) unwise (pp 133/4). All of these, interestingly, are also unethical in that inappropriate use of technology leads to less health than could be provided with the resources available.

Jennett is optimistic about the future of technology and its assessment, particularly as he believes that the traditional ethics of individualism in medicine is being eroded, partly as a result of the deployment of more technology. This is crucial to his analysis as one can only agree when he writes that 'rationalising the use of technology will be dependent on breaking through the barrier of clinical freedom behind which doctors are so fond of hiding'.

I have to wonder if his optimism on this issue is justified. Certainly his writing of such a book increases the probability that it is.

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Social Controls and the Medical Profession

Judith P Swazey and Stephen R Scher, editors, 268 pages, Boston, Mass, £27.50, Oelgeschlager, Gunn & Hain, Publishers Inc, 1985

This study is about professional standards and competence in medical practice, but it extends its discussion to fraudulent practices in scientific research, makes reference to other professions such as law and divinity, and includes some discussion of wider ethical issues. It is the result of collaboration between seventeen people representing various disciplines and professions. Amongst them were physicians and surgeons, psychiatrists, a minister of religion, a philosopher, sociologists, an historian of medicine and a lawyer. The project was supported by the National Science Foundation and the National Endowment for the Humanities of the USA. The participants held eleven inter-related conferences between 1980 and 1982, with Dr Judith Swazey as director.